CHILDREN'S REHABILITATIVE SERVICES

2009 FAMILY CENTERED SURVEY

EXECUTIVE SUMMARY

The mission of the ADHS Children Rehabilitative Services (CRS) program is to improve the quality of life for children by providing family centered medical treatment, rehabilitation, and related support services to enrolled individuals who have certain medical, handicapping, or potentially handicapping conditions. The family is the most important participant in the system of care for children with special healthcare needs (CSHCN). Thus, a family perception of the services received through the CRS program is crucial to its administration. The Family Centered Survey was created to evaluate the satisfaction of member families and is conducted annually.

Key Findings from the 2009 Family Centered Survey

- Overall, CRS care was rated at an average of 9.0 on a 10-point scale (with 10 being the highest level).
- Ninety-four percent of members had seen a CRS specialist in the past 12 months which was higher than last year survey response of 82 percent.
- The vast majority of respondents (92%) reported waiting times in the office were within 45 min.
- Of the respondents who needed urgent care, 34 percent were able to access urgent care within 72 hours which was lower than last year survey response of 47 percent.
- The majority of respondents (88%) reported that they were satisfied or very satisfied with how long it took to get urgent care.
- Sixty-four percent of respondents were able to obtain a clinic appointment within 45 days which was lower than 75 percent reported in 2008.
- Eighty-five percent of respondents were satisfied or very satisfied with how long it took to get their appointment.
- The vast majority of the respondents (91%) said they were usually or always involved as much as they wanted when decisions were made.
- Of those respondents that needed an interpreter, 93 percent always received translation services when they were requested and 96 percent were satisfied or very satisfied with the interpretersøassistance.

On June 25, 2008, ADHS awarded a statewide contract to Arizona Physicians IPA (APIPACRS) to deliver services to CRS members, effective October 1, 2008.

• The majority of respondents (84%) were aware of the contractor change. Of these respondents, 94 percent were satisfied or very satisfied with the change.

INTRODUCTION

The mission of the ADHS Children® Rehabilitative Services (CRS) program is to improve the quality of life for children by providing family centered medical treatment, rehabilitation, and related support services to enrolled individuals who have certain medical, handicapping, or potentially handicapping conditions. CRS specialists manage the overall care for what are often complicated medical conditions leading to more appropriate utilization of services and minimizing the need for emergency care. Four regional clinics throughout Arizona provide multi-specialty, interdisciplinary care to enrolled members. On June 25, 2008, ADHS awarded a statewide contract to Arizona Physicians IPA (APIPA-CRS) to deliver services to CRS members, effective October 1, 2008.

The family is the most important participant in the system of care for children with special healthcare needs (CSHCN). Thus, a family perception of the services received through the CRS program is crucial to its administration. The Family Centered Survey was created to evaluate the satisfaction of member families and is conducted annually.

This is the fourth year of the Family Centered Survey. The 2009 survey tool continues to be based upon the Consumer Assessment of Healthcare Providers and Systems (CAHPS) 3.0 Medicaid Managed Care Child Questionnaire, with modifications to accommodate the special population and program characteristics of CRS. This years survey includes five new questions to gather information on knowledge surrounding the transition to a new contractor, two new questions about internet and email access, and one question to assess satisfaction with interpreters. The telephone survey was administered to a representative sample of AHCCCS-enrolled CRS members under the age of 21. This year, the overall response rate was 40 percent.

The mean age of children represented by respondents was 9.2 years, with nearly 60 percent of children between the ages of four and fourteen. Fifty-five percent were male, and 62 percent were of Hispanic or Latino descent. Most of the members (59%) spoke English as their main language at home. An additional 24 percent spoke both English and Spanish at home and 8 percent spoke mainly Spanish. The most common diagnostic conditions were related to nervous system, circulatory system, musculoskeletal/connective tissue, and sense organ disorders. More demographic data on respondents can be found in Appendix A.

Throughout the report, 95 percent confidence intervals are denoted by õClö and the number of each question is listed in parentheses to provide for a quick reference to material in the appendices. Please see Appendix A for a description of the study methodology, Appendix B for a copy of the survey tool, Appendix C for a complete breakdown of the responses statewide, Appendix D for a comparison of responses by site, and Appendix E for an evaluation of cultural competency.

OVERALL HEALTH AND RATINGS OF CARE

Overall Care

Respondents were asked to rate their childøs overall health on a five-point scale ranging from excellent to poor (Q30). Nearly 64 percent of respondents characterized their childrenøs health as excellent or very good, with an additional 25 percent reporting a health rating of good. Eleven percent of respondents characterized their childøs health as fair or poor. When asked to rate the overall CRS health care (Q26), with 0 being the worst health care possible and 10 being the best health care possible, the average rating was 9.0 (CI=8.8, 9.2). Differences in ratings between clinic sites were not statistically significant, nor were there significant differences from the 2008 average rating (9.1).

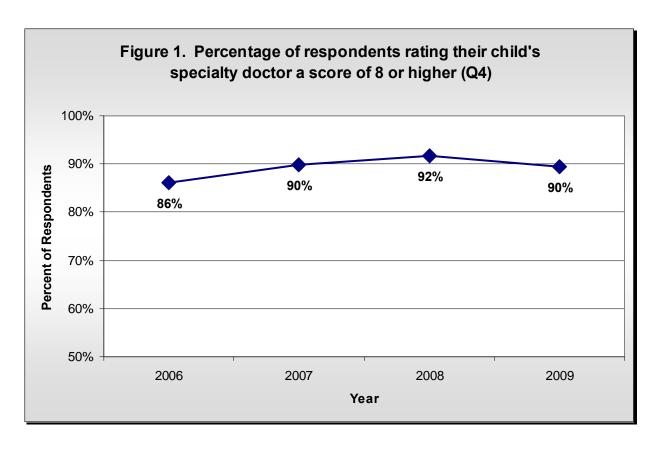
Specialty Care

As seen in Table 1, 94 percent of members had seen a CRS specialist in the past 12 months (Q1) which was higher than last year¢s survey response of 82 percent. This difference was statistically significant. Of those members who did not see a CRS specialist, only 26 percent (n=5) had attempted to get an appointment (Q2). Most parents/guardians (88%) reported that it was not a problem to see a CRS specialist when needed, 6 percent said it was a small problem, and 6 percent said it was a big problem (Q3). When compared to last year¢s survey, a larger number of families reported that there were no problems seeing a CRS specialist when needed.

Table 1. Questions Related to Specialty Care

Question	2006	2007	2008	2009
Q1. Saw a CRS specialty doctor in the last 12 months.				
	85%	86%	82%	94%
Q2. Tried to get an appointment in the last 12 months (Of				
those who did not see a CRS specialty doctor).	23%	10%	18%	26%
Q3. It was not a problem to see a CRS specialty doctor that				
your child needed to see in the last 12 months.	77%	80%	82%	88%
Q4. What number would you use to rate your childøs				
specialty doctor?	8.9	9.0	9.2	9.1

The average rating on a scale from 0 to 10, with 10 being the best specialist possible, was 9.1 (CI=8.9, 9.3). Ninety percent of respondents gave their childøs specialist a score of 8 or higher (Q4). The differences between results from 2008 to 2009 were not statistically significant (see Figure 1).



ACCESS TO CARE

Forty-three percent of respondents called the CRS clinic during regular clinic hours to get help or advice for their child (Q5), the majority of whom (81%) reported usually or always getting the help or advice they needed (Q6). Respondents were also asked about the number of emergency room visits made by their child. Twenty-one percent reported that their children visited an emergency room for their CRS condition (Q9).

AHCCCS has appointment standards for both primary care and specialty care. All of the care delivered at CRS clinics is specialty care. The following standards are outlined in the AHCCCS contract with CRS:

• For a CRS recipient with a medically urgent need, the CRS recipient must be seen according to the needs of the member and no later than 72 hours from the request.

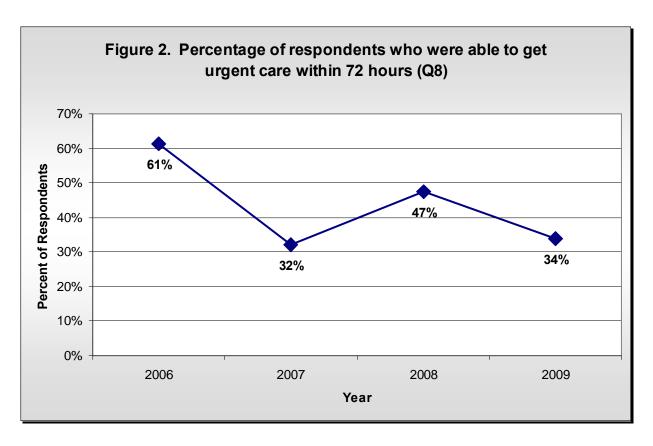
- A recipient
 ø waiting time for an appointment must not exceed 45 minutes, unless the
 provider is unavailable due to an emergency.

34% Received Urgent Care within 72 Hours

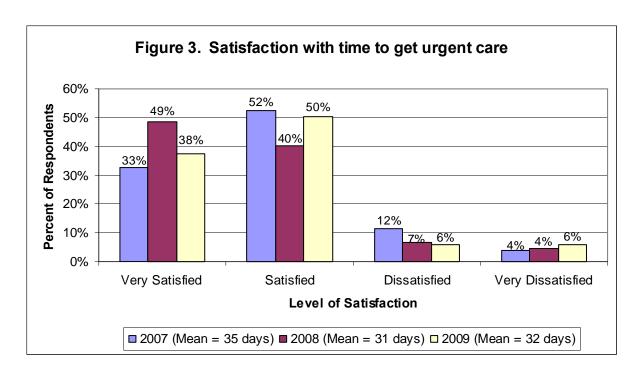
Urgent requests may involve conditions that are not covered under CRS, in which case the request is forwarded to the primary payer. When the condition is covered by CRS, a determination is made as to what kind of need the patient has, and whether it is more appropriate to go to a physicianøs office or be seen at a clinic at the next scheduled visit.

Survey respondents were asked whether in the past year their children oneeded care right away for their CRS conditiono (Q7) and if so, how long they had to wait to get care at a CRS clinic (Q8). These questions were used to assess compliance with the AHCCCS urgent care standard, although there may be limitations to their applicability since CRS clinics do not provide urgent care in the usual sense of the word.

More than half of the respondents (53%) reported that their child did not need urgent care for their CRS condition (Q7). Of those who needed urgent care, 34 percent (CI= 26, 41) said they were able to get it in a CRS clinic within 72 hours (Q8). This was lower from 2008, where 47 percent were able to get urgent care at a CRS clinic within 72 hours (see Figure 2). This difference was statistically significant. However, differences between clinic sites were not statistically significant.

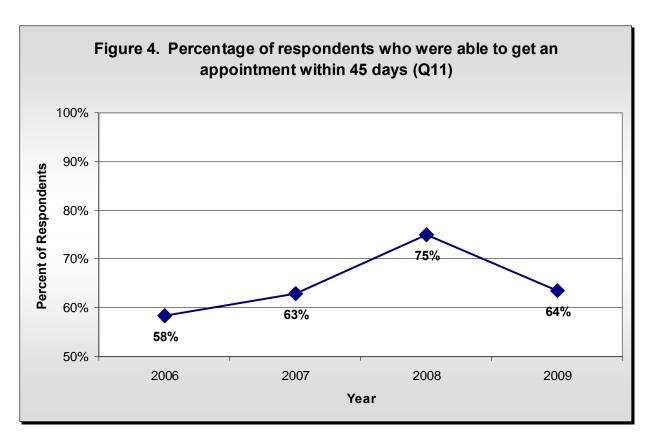


The majority of respondents (88%) reported being satisfied or very satisfied with how long it took to get urgent care (Q7). There were no significant differences in satisfaction level by site, nor were there significant differences from the 2008 survey results. Among the very satisfied respondents, 44 percent received urgent care within 3 days. As seen in Figure 3, the average time reported to get urgent care was 32 days, with responses ranging from less than one day to one year.

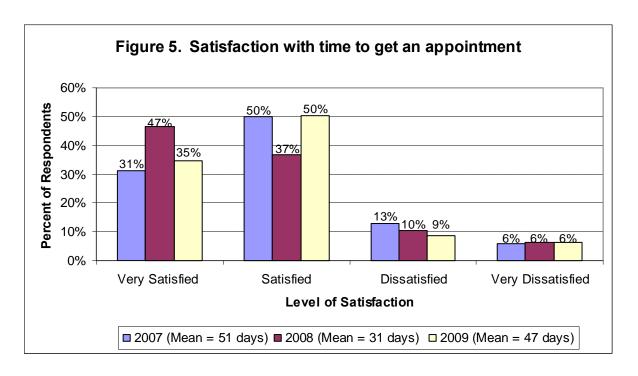


64% Received Appointment within 45 Days

Seventy-five percent of respondents reported calling a CRS clinic for an appointment in the past 12 months (Q10). Of those, 64 percent (CI=57, 70) were able to get one within 45 days (Q11). This was lower from 2008, where 75 percent were able to get an appointment at a CRS clinic within 45 days (see Figure 4). This difference was statistically significant.



The majority (85%) reported being satisfied or very satisfied with how long it took to get their appointments which was similar to last year's response of 84 percent (Q10). There were no statistically significant differences by site. When the categories of satisfied and very satisfied responses were analyzed separately, there were statistically significant differences by survey year (see Figure 5). Seventy-five percent of very satisfied respondents received an appointment within 45 days or less. The average time that participants reported waiting to get an appointment at a CRS clinic was 47 days, with responses ranging from less than one day to one year. This was higher than the 2008 average of 31 days. This difference was statistically significant.



92% Waited Less Than 45 Minutes Before Being Taken to Exam Room

During a CRS specialty clinic appointment, several specialists may see a patient in the same day. It is not uncommon for patients to spend a substantial amount of time at the clinic seeing multiple specialists and social service staff. When respondents were asked to report their wait time before being taken to the exam room, 92 percent (CI=88, 95) reported that they usually waited 45 minutes or less (Q13). The percentage of respondents who waited less than 15 minutes in 2009 (51%) was higher than in 2008 (39%). This difference was statistically significant. However, differences between clinic sites were not statistically significant.

MEMBER SERVICE AND TREATMENT

At CRS clinics, youth may not feel so conspicuously different because the staff are familiar with them and understand their conditions. CRS clinics are places where children and youth do not have to explain how they are different or their need for special accommodations.

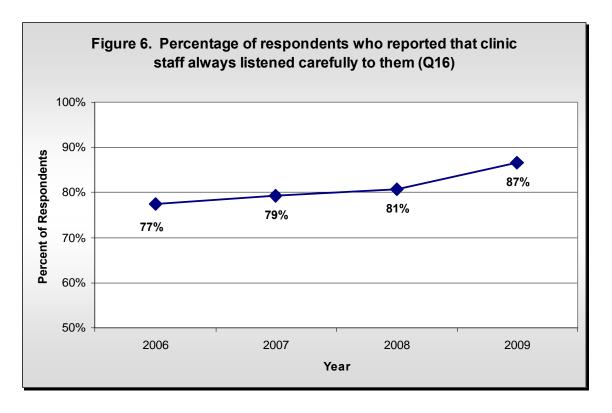
Several survey items asked about the way that children and their families were treated by clinic staff (see Table 2). Eighty-six percent felt that the clinic staff were always as helpful as

they should be (Q15). Similarly, high proportions were reported for other customer service measures. Eighty percent of respondents said that they always had their questions answered by their CRS providers (Q20) and 82 percent always received information that was needed from their CRS providers (Q21). Respondents who usually or always had their questions answered were more likely to rate their childs overall health as good or better.

Table 2. Questions Related to Member Service

Question	2006	2007	2008	2009
Q15. Staff were always as helpful as you thought they should				
be.	75%	80%	82%	86%
Q20. You always had your questions answered by your childes				
CRS doctors or other health providers.	78%	80%	83%	80%
Q21. You always received information you needed from your				
childøs CRS doctor or other health providers.	76%	76%	81%	82%

Eighty-seven percent of respondents reported that clinic staff always listened carefully to them (Q16). This was a significant improvement from the 81 percent reported in 2008 (see Figure 6).



It is widely accepted that having families of children with special health care needs involved in all levels of decision making is a best practice. Several questions were asked regarding the processes by which decisions about the childøs health care were made. Half of the respondents (50%, CI=44, 56) reported that decisions about their childrenøs health care were made during CRS visits (Q22).

Table 3 shows the results of questions related to family involvement in decision making. When decisions were made, the majority (87%) reported usually or always being offered choices about their childøs health care (Q23). When decisions were made, 85 percent reported usually or always being asked to tell the health care provider what choices they prefer (Q24). The vast majority of the respondents (91%) said they were usually or always involved as much as they wanted when decisions were made (Q25). This was lower than last yearøs survey response of 99 percent. This difference was statistically significant.

Table 3. Questions Related to Decision Making

Question	2006	2007	2008	2009
Q23. When decisions were made, your childøs provider usually or always offered you choices about your childøs health care.	76%	87%	92%	87%
Q24. When decisions were made, your childøs provider usually or always asked you to tell them what choices you prefer.	74%	90%	90%	85%
Q25. When decisions were made, your childøs provider usually or always involved you as much as you wanted.	90%	90%	99%	91%

Two additional questions were included in the 2009 survey relating to awareness of who to call if families have a problem with CRS. Of the respondents, 66 percent knew they could call APIPA-CRS Member Services 24 hours a day, 7 days a week (Q34) and 58 percent knew they could call the Office for Children with Special Health Care Needs if they had a problem with CRS (Q35). Two new questions about internet and email access were also added to the 2009 survey. Among the respondents, 61 percent had internet access (Q36), of whom 86 percent had

an email account (Q37). Overall, 52 percent of respondents had an email address regardless of whether or not they had access to the internet.

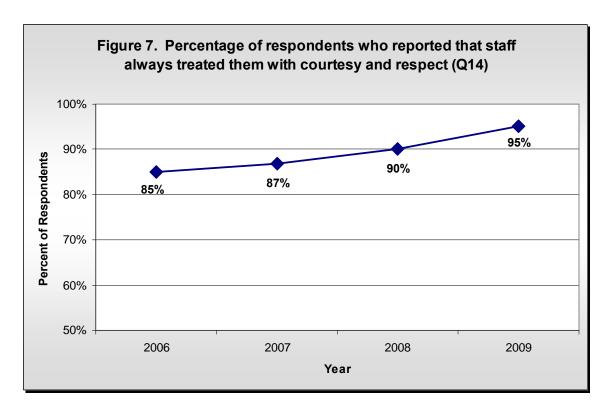
CULTURAL COMPETENCY

Communication between families and CRS clinic staff, including the need for translation services, are an important component of a culturally competent program. Families were asked about the clinic staff¢s ability to show respect and explain things in a way that family members could understand regardless of language spoken. Eighty-five percent of respondents said that clinic staff always explained things to them in a way they could understand (Q17). Additionally, 85 percent reported that CRS doctors or other health providers always showed respect for what they had to say (Q18) and always made it easy to discuss their questions and concerns (Q19).

Table 4. Questions Related to Cultural Competency

Question	2006	2007	2008	2009
Q17. Staff always explained things in a way you could				
understand.	79%	83%	87%	85%
Q18. CRS doctors or other health providers always showed				
respect for what you had to say.	77%	84%	86%	85%
Q19. CRS doctors or other health providers always made it				
easy for you to discuss your questions or concerns.	80%	80%	84%	85%

The vast majority of respondents (95%) said they were always treated with courtesy and respect (Q14). This was higher than the reported 90 percent in 2008 (see Figure 7). This difference was statistically significant.



Families were also asked about the need for and the delivery of translation services.

Approximately 29 percent of respondents needed an interpreter within the last 12 months (Q27).

Of those respondents that needed an interpreter, 93 percent always received translation services when they were requested (Q28) and 96 percent were satisfied or very satisfied with the interpretersøassistance (Q29).

The results to questions involving cultural competency were also evaluated by racial/ethnic group (see Appendix E). There were no statistical differences found when the responses of White, Non-Hispanic families were compared to those of minority families or when responses of Hispanic families were compared to those of Non-Hispanic families. Additionally, the responses of survey participants who needed an interpreter were compared to the responses of those who did not need an interpreter. No statistical differences between the groups existed for the questions related to cultural competency.

APIPA-CRS

Five new questions were added to reflect member awareness of the transition to the new contractor, Arizona Physicians IPA (APIPA-CRS), effective October 1, 2008. The majority of respondents (84%) were aware of the contractor change (Q31). Of these respondents, 94 percent were satisfied or very satisfied with the change (Q32). The new contract allowed for the expansion of pharmacy locations. Over half of the respondents (59%) were aware of this change (Q33).

DISCUSSION

As in previous years, CRS families continue to characterize their childøs overall health status favorably. Eighty-nine percent of respondents reported that their childrenøs health was excellent, very good, or good, despite their medical challenges. Overall, CRS care was rated at an average of 9.0 on a 10-point scale (with 10 being the highest level).

This year's survey revealed that a larger number of families had no problems seeing a CRS specialist when needed. Ninety-four percent of members had seen a CRS specialist in the past 12 months which was higher than last year's survey response of 82 percent. Satisfaction levels remained high in 2009, indicating that families felt they were well-informed and were treated with courtesy and respect by CRS doctors and clinic staff. The vast majority of the respondents (91%) said they were usually or always involved as much as they wanted when decisions were made.

Information was collected to evaluate compliance with AHCCCS standards on access to care for clinic appointments. Performance on two out of the three standards was low but satisfaction levels of respondents remained high. The majority of respondents (92%) reported

waiting times in the office were within standards (45 min). The percentage of respondents who waited less than 15 minutes in 2009 (51%) was higher than in 2008 (39%).

Sixty-four percent of respondents were able to obtain a clinic appointment within 45 days which was lower than 75 percent reported in 2008. Although performance declined, the majority of respondents (85%) were satisfied or very satisfied with how long it took to get their appointment.

Of the respondents who needed urgent care, 34 percent were able to access urgent care within 72 hours. This was lower than last year's survey response of 47 percent. However, 88 percent of respondents reported that they were satisfied or very satisfied with how long it took to get urgent care.

The 2009 survey included two additional questions relating to awareness of who to call if families have a problem with CRS. Of the respondents, 66 percent knew they could call APIPA-CRS Member Services 24 hours a day, 7 days a week and 58 percent knew they could call the Office for Children with Special Health Care Needs if they had a problem with CRS.

During the survey, some respondents needed more information about CRS or had complaints about their experiences with CRS. For these cases, CRSA Member Services either assisted the member or referred them to CRSA Quality Management or APIPA-CRS Member Services for follow-up. During follow-up calls, respondents expressed difficulty in understanding definitions and areas within the New Member Orientation Packet and asked for further clarification or alternative information.

A high proportion of wrong numbers was again a problem in the administration of this year survey (34%). This poses a problem not only for survey purposes, but more importantly, for contacting patients about their health care. It is unknown whether wrong numbers resulted

from the clinicsøsystematic lack of updating patient information, from patients intentionally withholding contact information, or members simply failing to update their records when contact information changes. Responses to new questions in the 2009 survey revealed that 61 percent of families had internet access, of which 86 percent had an email account. Overall, 52 percent of respondents had an email address regardless of whether or not they had access to the internet.

Seventeen percent of respondents required translation of the survey into Spanish and were easily accommodated by phone interviewers. Translation services were available for languages other than Spanish, although no respondents requested translation this year.

Responses to questions relating to cultural competency remained positive. Of the respondents that needed an interpreter, 93 percent always received translation services when they were requested and 96 percent were satisfied or very satisfied with the interpretersøassistance.

The majority of members in all racial/ethnic groups reported high satisfaction levels in 2009.

CRS strives to continue the trend of positive feedback from families reporting that staff were culturally sensitive and respectful.

RECOMMENDATIONS

- The CRSA Division of Member Services should work with community partners to increase
 awareness among families on how to contact APIPA-CRS Member Services or the Office for
 Children with Special Health Care Needs when they have questions or concerns about the
 CRS program.
- The CRSA Division of Member Services should update the New Member Orientation Packet definition and acronym list.
- The CRSA Division of Member Services should develop online resources for families who have children with CRS eligible conditions and for families with children enrolled in the CRS program.
- APIPA-CRS should explore ways to improve reliability of contact information (e.g. verifying information at all points of contact such as clinic appointments and Member Service calls).

APPENDIX A: METHODOLOGY

Sample Selection

The sampling frame included all CRS members less than 21 years of age who were continuously enrolled in CRS between January 1, 2008 and December 31, 2008. Members with a gap in enrollment of more than 30 days were excluded. The sampling frame included a total of 17,130 members, 16,299 of which were AHCCCS-enrolled. A sample size of 377 was calculated to tolerate no more than a 5% margin of error at a 95% confidence level, using the following formulas:

$$n = {Nx \choose ((N-1)E^2 + x)}$$

$$x = z^2 p(1-p)$$

*N was rounded to 20,000 for use in the calculations

where N = number of members in the sampling frame (population)

n = minimum sample size,

z = the distance from the mean associated with confidence level (1.96 for a

95% confidence level),

E = margin of error (.05)

p = the estimated proportion expected to be associated with a given value of a variable (the most conservative assumption = 0.5).

The Family Centered Survey response rate in 2008 was 46%; thus, a simple random sample of 820 members (377/0.46 = 820) was drawn using SPSS version 14.0. Among these 820 members, 782 were enrolled in AHCCCS. The results shown in this report are only for the respondents who were AHCCCS enrolled in 2008.

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Survey Administration

The survey tool is based primarily on the Consumer Assessment of Healthcare

Providers and Systems (CAHPS) 3.0 Medicaid Managed Care Child Questionnaire, with

modifications to accommodate the special population and program characteristics of CRS

(see Appendix B). It also includes five new questions to gather information on knowledge

surrounding the transition to a new contractor, two new questions about internet and email

access, and one question to assess satisfaction with interpreters. Two questions that were meant
to provide additional insight into cultural competency, which were originally from the Mental

Health Statistics Improvement Program (MHSIP) Youth Services Survey, have been deleted.

The tool was translated into Spanish to accommodate the high percentage of Spanish-speaking
families in the CRS program. Translation services were available for languages other than

Spanish, although no respondents requested translation this year.

The survey was administered by four temporary phone interviewers and one OCSHCN staff member. Two interviewers were able to conduct interviews with Spanish-speaking respondents. The data entry tool was populated with membersøcontact information and key demographic variables. Interviewers were trained on the data entry tool, and its ability to accurately capture data was verified before survey implementation. In addition, training about the fundamental aspects of how CRS clinics operate was conducted.

Some respondents who were reached by phone needed more information about the CRS program or had complaints about their experiences with CRS. For these cases, the interviewer submitted a descriptive form to CRSA Member Services who either assisted the member or referred them for follow-up. Six complaints were referred to Quality Management, of which five

were determined to be quality of care issues. Only one (20%) of these cases was substantiated. Additionally, 25 complaints were referred to APIPA-CRS Member Services for follow-up.

Members were tracked using cards containing their contact information, as well as the date, time and result of each survey attempt. Cards were then organized according to the number of attempts made, need for translation, and the preferred time of day to call the member, when indicated. Up to 12 call attempts were made for each member; calls were made between the hours of 10am to 6pm on weekdays and weekends. Survey administration began January 19th and continued until March 30, 2009.

Analysis

Survey data was collected in MS Access and exported to SPSS 17.0 for analysis.

Response rates and key outcomes were calculated by site. Within the body of this report, only valid responses are displayed (i.e., valid responses exclude those responses which were either not applicable or missing). Appendix C is a complete breakdown of statewide results including missing values, and Appendix D is a comparison of results by site.

Ninety-five percent confidence intervals were calculated for point estimates using SPSS and the following formula:

$$p \pm z*sqrt[p(1-p)/n]$$

where p = the calculated proportion of a given variable

z = the distance from the mean associated with confidence level (1.96 for a 95% confidence level)

n = the number of respondents

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When findings were presented as statistically significant, differences in proportions or means were tested at p < 0.05.

Results

Of the 782 AHCCCS-enrolled CRS members within the sample, 463 were successfully contacted, giving an initial response rate of 59%. Thirteen members were no longer in the program, decreasing the total eligible sample to 769. Accounting for refusals to complete the survey and members who were not reached at a convenient time to participate, 314 surveys were completed, giving an adjusted response rate of 40%. Response rates at the site level varied from a low of 22% to a high of 61% and were similar to last years rates. The site-level response rates were not significantly different from those in 2008. Over one-third (34%) of sampled members could not be reached due to wrong or disconnected numbers.

Table A1: Family Centered Survey Response Rates by Site, n=782

CRS Regional Clinic Site	Number of Sampled Members*	Number of Survey Respondents	Response Rate
Phoenix	492	210	43%
Tucson	180	68	38%
Flagstaff	79	17	22%
Yuma	31	19	61%

Demographic Characteristics of Respondents vs. Population (AHCCCS-Enrolled)

The mean age of children represented by respondents was 9.2 years, with nearly 60% of children between the ages of 4 and 14; 55% were male, and 62% were of Hispanic or Latino descent. Most of the members (59%) spoke English as their main language at home. An additional 24% spoke both English and Spanish at home and 8% spoke mainly Spanish. The most common diagnostic conditions were related to nervous system, circulatory system, musculoskeletal/connective tissue, and sense organ disorders.

Without a census, it is possible that the members who completed the survey had different opinions than the CRS population as a whole. This would imply that estimates from the survey

data were inaccurate, or *biased*. One way to evaluate the potential for bias is to compare respondents to the original sampling population on known characteristics, such as age, sex, ethnicity, and enrolling diagnosis. Race data was not used as data from the CRS system was inadequate to allow for a comparison; over 80% of respondents had no known race category.

Respondents were similar to the population in terms of age, sex, and most enrolling diagnoses. However, there was a statistically significant difference between the proportion of Hispanic respondents and the proportion of Hispanic members in the population. Sixty-two percent of survey respondents were Hispanic, while only 49% of the CRS population was identified as such. Other differences in results related to ethnicity are addressed within the body of the report and in Appendix E.

Table A2: Demographic Characteristics of Respondents vs. Population

Characteristic	Respo	ondents	Population		
	(n=	314)	(N=16	(N=16,299)	
	n	%	n	%	
Age ó Mean (95% CI)	9.2 (8.6 - 9.8)		9.5 (9.4 - 9.6)		
< 1	0	0	1	0	
1-3	54	17.2	2803	17.2	
4-9	125	39.8	5859	35.9	
10-14	63	20.1	3867	23.7	
15-17	45	14.3	2125	13.0	
18-21	27	8.6	1644	10.1	
Sex					
Male	171	54.5	8709	53.4	
Female	143	45.4	7590	46.6	
Ethnicity*					
Hispanic/Latino descent**	114	61.9	7897	48.5	
Not Hispanic/Latino	185	38.1	8402	51.5	
Disease Class					
Blood & Blood Forming Organs	1	0.3	92	0.6	
Circulatory System	64	20.4	3571	21.9	
Congenital Anomalies	6	1.9	211	1.3	
Digestive System	25	8.0	1164	7.1	
Endocrine, Nutritional, Metabolic	13	4.1	648	4.0	
Genitourinary System*	13	4.1	676	4.1	
Musculoskeletal/Connective*	48	15.3	3024	18.6	
Neoplasm	8	2.5	368	2.3	
Nervous System*	82	26.1	4069	25.0	
Other	4	1.3	220	1.3	
Respiratory System	2	0.6	66	0.4	
Sense Organs	47	15.0	2140	13.1	
Skin & Subcutaneous Tissue	1	0.3	50	0.3	

^{*15} respondents did not report ethnicity.

^{**}Respondents are significantly different from Population

APPENDIX B: FAMILY CENTERED SURVEY, 2008

Family Centered Survey

All information that would let someone identify you or your family will be kept private. The Arizona Department of Health Services, Office for Children with Special Health Care Needs will not share your personal information with anyone without your OK. You may choose to answer this survey or not. If you choose not to, this will not affect the benefits your child receives.

If you want to know more about this survey, please call Thara MacLaren at (602) 542-2881.

Nar	ne o	of the child:	Gender of child
Quali	fyin	ing Condition:	
Parer	nt/gu	guardian Name:	
Phone	e nu	number:	
	Ph	Phone disconnected	
	No	No answer, RECORD DATE, TIME AND OUTCO	OME
	Ph	Phone answered	
	the pre	Hello, this is (INTERVIEWER NAME) Department of Health Services. We'd like to talk with the Children's Rehabilitative Services Program. No program better. May I please speak to (Parent/Guber she is 18 or older)	with you about your experiences with our answers will help us to make the
		□ If person is parent/guardian, GO TO CONSE I	NT
	<u> </u>	No one by that name at this phone num	ber, RECORD DATE, TIME AND
		□ Not available	
		We need to talk with the parent or guardian w knows the most about the health care that (ch receives through CRS.	
		Would that be you?	
	<u> </u>	Yes, GO TO SURVEY INTRODUCTION No	
		Who would that be?	Is he/she available?
		Yes GO TO SURVEY INTRODUCTION No, GO TO CALL BACK	
		BACK:	
	Ы		eed Spanish speaker other language

SURVEY INTRODUCTION

We are conducting a satisfaction survey of families who receive health care services through Children's Rehabilitative Services (CRS). Your family has been selected at random to be included in the study. Your answers will help us to make the program better.

You may choose to do this interview or not. If you do, your responses will be kept private. Your decision to do the interview will not affect any benefits you get. The questions should take about 15 minutes to answer.

Will yo	u participate in this survey?
	Parent/guardian agrees
	Parent/guardian refuses, Thank them for their time and say good-bye.
	FAMILY MEMBER DOES NOT HAVE TIME TO PARTICIPATE IN THE /IEW NOW, GO TO CALL BACK.
	to begin the interview now, but before we begin, do you have any ons about the survey?
•	arent or guardian has additional questions or concerns have them call Thara en at (602) 542-2881.
	Yes No, Thank them for their time
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	see a CRS specialty doctor? ¹☐ Yes → If Yes, Go to Question 3 ¹☐ No → If No, Skip Question 4	3.	CRS clinic during regular clinic hours to get help or advice for your child? 1 ☐ Yes 2 ☐ No → If No, Go to Question 7
2.	In the past 12 months, did you try to get an appointment with a CRS specialty doctor? ¹□ Yes □□ No → If No, Go to Question 5	6.	In the last 12 months, when you called during regular CRS clinic hours, how often did you get the help or advice you needed for your child? 1 Never
3.	In the last 12 months, how much of a problem, if any, was it to see a CRS specialty doctor that your child needed to see?		² ☐ Sometimes ³ ☐ Usually ⁴ ☐ Always
	 A big problem A small problem Not a problem 	7.	In the last 12 months, when your child needed care right away for their CRS condition, how satisfied were you with how long it took to get care at a CRS clinic?
4.	We want to know your rating of the CRS specialty doctor your child saw most often in the last 12 months. Using any number from 0 to 10, where 0 is the worst specialist possible, and 10 is the best specialist possible, what number would you use to rate your child's specialty doctor?		 Very satisfied Satisfied Dissatisfied Very dissatisfied My child did not need urgent care Go to Question 9
	0 □ 0 Worst specialist possible 1 □ 1 1 2 □ 2 3 □ 3 4 □ 4 5 □ 5 6 □ 6 6 7 □ 7 8 □ 8 9 □ 9 9 10 □ 10 Best specialist possible	8.	In the last 12 months, when your child needed care right away for their CRS condition, most of the time, how long did you have to wait to get care at a CRS clinic? days weeks months I could not get an appointment

9.	In the last 12 months, how many times did your child go to an emergency room for their CRS condition?	12.	In the last 12 months, not counting the times your child went to an emergency room, how many times did your child go to the CRS clinic?
	 None 1		 None → Go to Question 30 1
11.	In the last 12 months, not counting the times your child needed care right away, how satisfied were you with how long it took to get an appointment at a CRS clinic? ¹□ Very satisfied ²□ Satisfied ³□ Dissatisfied ⁵□ I did not try to get an appointment → Go to Question 12 In the last 12 months, when you called to schedule an appointment for your child at the CRS clinic, most of the time, how long did you have to wait for an appointment? □ days □ weeks □ months □ I could not get an appointment	14.	In the last 12 months, when you had an appointment at the CRS clinic, how long after your appointment time, did your child have to wait to be taken to the exam room? Less than 15 minutes 15 . 30 minutes 31 . 45 minutes 46 . 60 minutes More than an hour In the last 12 months, how often did office staff at your child's CRS clinic treat you and your child with courtesy and respect? Never Sometimes Usually Always

15.	In the last 12 months, how often were office staff at your child's CRS clinic as helpful as you thought they should be? 1 Never 2 Sometimes 3 Usually 4 Always	19.	In the last 12 months, how often did your child's CRS doctors or other health providers make it easy for you to discuss your questions or concerns? 1 Never 2 Sometimes 3 Usually
16.	In the last 12 months, how often did the CRS clinic staff listen carefully to you?		 Always I didnot have any questions → Go to Question 21
	 Never Sometimes Usually Always 	20.	In the last 12 months, how often did you have your questions answered by your child's CRS doctors or other health providers?
17.	In the last 12 months, how often did your child's CRS doctors or other health providers explain things in a way you could understand?		 Never Sometimes Usually Always
	 Never Sometimes Usually Always 	21.	In the last 12 months, how often did you get the specific information you needed from your child's CRS doctors or other health providers?
18.	In the last 12 months, how often did your child's CRS doctors or other health providers show respect for what you had to say? 1 Never 2 Sometimes 3 Usually		 Never Sometimes Usually Always I didno need any information
	⁴ □ Always	22.	In the last 12 months, were any decisions about your child's health care made during your CRS visits? ¹□ Yes □□ No → If No, Go to Question 26

23.	last 12 months, how often did your child's CRS doctors or other health providers offer you choices about your child's health care?	26.	where 0 is the worst health care possible, and 10 is the best health care possible, what number would you use to rate all your child's CRS health care in the last 12 months?
	² ☐ Sometimes ³ ☐ Usually ⁴ ☐ Always		 0 Worst health care possible 1 1 2 2 3 3 4 4
24.	When decisions were made in the last 12 months, how often did your child's doctors or other health providers ask you to tell them what choices you prefer? 1 Never 2 Sometimes 3 Usually 4 Always	0.7	5
25.	When decisions were made in the last 12 months, how often did your child's CRS doctors or other health providers involve you as much as you wanted? 1 Never 2 Sometimes 3 Usually 4 Always	28.	An interpreter is someone who repeats or signs what one person says in a language used by another person. In the last 12 months, did you need an interpreter to help you speak with your child's CRS doctors or other health providers? ¹□ Yes ¹□ No → If No, Go to Question 30 In the last 12 months, when you needed an interpreter to help you speak with your child's CRS doctors or other health providers, how often did you get one? ¹□ Never ²□ Sometimes
			³ ☐ Usually ⁴ ☐ Always

29.	How satisfied were you with the interpreters' assistance?	34.	APIPA-CRS Member Services 24
	¹ □ Very satisfied ² □ Satisfied		hours a day, 7 days a week if you have a problem with CRS?
	³☐ Dissatisfied		¹□ Yes
	⁴ ☐ Very dissatisfied		² □ No
30.	In general, how would you rate your child's overall health now?	35.	Did you know that you can call the Arizona Department of Health Services, Office for Children with Special Health Care Needs if you have a problem with CRS?
	¹☐ Excellent		¹□ Yes
	² □ Very Good ³ □ Good		² □ No
	⁴ □ Fair	36.	Do you have access to the internet?
	⁵ □ Poor	30.	<u> </u>
			¹□ Yes º□ No
31.	On Oct 1 st , the CRS contractor		
	changed to APIPA-CRS. Are you aware of that change?	37.	Do you have an email account?
	¹□ Yes		¹□ Yes
	⁰ □ No → If No, Go to Question 33		⁰ □ No
32.	How satisfied are you with the	38.	Is your child of Hispanic or Latino origin or descent?
	change?		¹☐ Yes, Hispanic or Latino
	¹ □ Very satisfied ² □ Satisfied		⁰ ☐ No, Not Hispanic or Latino
	³☐ Dissatisfied		
	⁴ □ Very dissatisfied	39.	What is your child's race? Please mark one or more.
			¹☐ White
33.	Since Oct 1 st , there are now more		² ☐ Black or African-American
	locations where you can get a CRS prescription filled. Are you aware of		³ □ Asian ⁴ □ Native Hawaiian or other
	that change?		Pacific Islander
	¹□ Yes		⁵ American Indian or Alaska Native
	⁰ □ No		⁶ □ Other

40.	What is the highest grade or level of school that you have completed?	42.	What language does your child mainly speak at home?
	¹☐ 8th grade or less		¹□ English
	² ☐ Some high school, but did not		² ☐ Spanish
	graduate		³☐ Some other language
	³ ☐ High school graduate or GED		(please print)
	⁴ ☐ Some college or 2-year degree		
	⁵ ☐ 4-year college graduate	43.	How are you related to the child?
	⁶ ☐ More than 4-year college degree		¹ Mother or father
			² ☐ Grandparent
			³ ☐ Aunt or uncle
41.	What language do you mainly speak		⁴ ☐ Older brother or sister
	at home?		⁵ ☐ Other relative
	¹□ English		⁶ □ Legal guardian
	² □ Spanish		⁷ □ Self
	³ ☐ Some other language		⁸ ☐ Someone else <i>(please print)</i>
	(please print)		
			Thank you for completing this survey

APPENDIX C: SURVEY RESPONSES, STATEWIDE

1. In the last 12 months, did your child see a CRS specialty doctor?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	19	6.1	6.1	6.1
	Yes	295	93.9	93.9	100.0
	Total	314	100.0	100.0	

2. In the past 12 months, did you try to get an appointment with a CRS specialty doctor?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	14	73.7	73.7	73.7
	Yes	5	26.3	26.3	100.0
	Total	19	100.0	100.0	

3. In the last 12 months, how much of a problem, if any, was it to see a CRS specialty doctor that your child needed to see?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	A big problem	18	5.7	6.0	6.0
	A small problem	18	5.7	6.0	12.0
	Not a problem	264	84.1	88.0	100.0
	Total	300	95.5	100.0	
Missing	System	14	4.5		
	Total	314	100.0		

4. What number would you use to rate your child's specialty doctor?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 to 3	5	1.7	1.7	1.7
	4 to 7	26	8.8	8.8	10.5
	8 to 10	264	89.5	89.5	100.0
	Total	295	100.0	100.0	

Mean = 9.06, Standard Deviation = 1.66

5. In the last 12 months, did you call the CRS clinic during regular clinic hours to get help or advice for your child?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	180	57.3	57.5	57.5
	Yes	133	42.4	42.5	100.0
	Total	313	99.7	100.0	
Missing	System	1	.3		
	Total	314	100.0		

6. In the last 12 months, when you called during regular CRS clinic hours, how often did you get the help or advice you needed for your child?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	7	5.3	5.3	5.3
	Sometimes	18	13.5	13.5	18.8
	Usually	17	12.8	12.8	31.6
	Always	91	68.4	68.4	100.0
	Total	133	100.0	100.0	

7. In the last 12 months, when your child needed care right away for their CRS condition, how satisfied were you with how long it took to get care at a CRS clinic?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very Satisfied	56	17.8	37.6	37.6
	Satisfied	75	23.9	50.3	87.9
	Dissatisfied	9	2.9	6.0	94.0
	Very Dissatisfied	9	2.9	6.0	100.0
	Total	149	47.5	100.0	
Missing	My child did not need urgent care	165	52.5		
	Total	314	100.0		

8. In the last 12 months, when your child needed care right away for their CRS condition, most of the time, how long did you have to wait to get care at a CRS clinic?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Within 3 Days	50	33.6	33.8	33.8
	4-7 days	16	10.7	10.8	44.6
	More than 7 days	70	47.0	47.3	91.9
	Could not get an appointment	12	8.1	8.1	100.0
	Total	148	99.3	100.0	
Missing	System	1	.7		
	Total	149	100.0		

Mean = 32.3 days, Standard Deviation = 62.8 days

9. In the last 12 months, how many times did your child go to an emergency room for their CRS condition?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	None	245	78.0	79.0	79.0
	1	31	9.9	10.0	89.0
	2	12	3.8	3.9	92.9
	3	8	2.5	2.6	95.5
	4	3	1.0	1.0	96.5
	5 to 9	7	2.2	2.3	98.7
	10 or more	4	1.3	1.3	100.0
	Total	310	98.7	100.0	
Missing	System	4	1.3		
	Total	314	100.0		

10. In the last 12 months, not counting the times your child needed care right away, how satisfied were you with how long it took to get an appointment at a CRS clinic?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very Satisfied	82	26.1	34.7	34.7
	Satisfied	119	37.9	50.4	85.2
	Dissatisfied	20	6.4	8.5	93.6
	Very Dissatisfied	15	4.8	6.4	100.0
	Total	236	75.2	100.0	
Missing	I did not try to get an appointment	78	24.8		
	Total	314	100.0		

11. In the last 12 months, when you called to schedule an appointment for your child at the CRS clinic, most of the time, how long did you have to wait for an appointment?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	45 Days or less	148	62.7	63.5	63.5
	46 to 90 days	19	8.1	8.2	71.7
	More than 90 days	45	19.1	19.3	91.0
	Could not get an appointment	21	8.9	9.0	100.0
	Total	233	98.7	100.0	
Missing	System	3	1.3		
	Total	236	100.0		

Mean = 46.8 days, Standard Deviation = 66.8 days

12. In the last 12 months, not counting the times your child went to an emergency room, how many times did your child go to the CRS clinic?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	None	27	8.6	8.6	8.6
	1	74	23.6	23.6	32.2
	2	67	21.3	21.3	53.5
	3	38	12.1	12.1	65.6
	4	29	9.2	9.2	74.8
	5 to 9	49	15.6	15.6	90.4
	10 or more	30	9.6	9.6	100.0
	Total	314	100.0	100.0	

13. In the last 12 months, when you had an appointment at the CRS clinic, how long after your appointment time, did your child have to wait to be taken to the exam room?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Less than 15 minutes	145	50.5	50.5	50.5
	15-30 minutes	99	34.5	34.5	85.0
	31-45 minutes	19	6.6	6.6	91.6
	46-60 minutes	13	4.5	4.5	96.2
	More than an hour	11	3.8	3.8	100.0
	Total	287	100.0	100.0	

14. In the last 12 months, how often did office staff at your child's CRS clinic treat you and your child with courtesy and respect?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	2	.7	.7	.7
	Sometimes	6	2.1	2.1	2.8
	Usually	6	2.1	2.1	4.9
	Always	273	95.1	95.1	100.0
	Total	287	100.0	100.0	

15. In the last 12 months, how often were office staff at your child's CRS clinic as helpful as you thought they should be?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	4	1.4	1.4	1.4
	Sometimes	12	4.2	4.2	5.6
	Usually	23	8.0	8.0	13.6
	Always	247	86.1	86.4	100.0
	Total	286	99.7	100.0	
Missing	System	1	.3		
	Total	287	100.0		

16. In the last 12 months, how often did the CRS clinic staff listen carefully to you?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	4	1.4	1.4	1.4
	Sometimes	9	3.1	3.2	4.6
	Usually	25	8.7	8.8	13.4
	Always	245	85.4	86.6	100.0
	Total	283	98.6	100.0	
Missing	System	4	1.4		
	Total	287	100.0		

17. In the last 12 months, how often did your child's CRS doctors or other health providers explain things in a way you could understand?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	1	.3	.3	.3
	Sometimes	12	4.2	4.2	4.5
	Usually	30	10.5	10.5	15.0
	Always	243	84.7	85.0	100.0
	Total	286	99.7	100.0	
Missing	System	1	.3		
	Total	287	100.0		

18. In the last 12 months, how often did your child's CRS doctors or other health providers show respect for what you had to say?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	5	1.7	1.8	1.8
	Sometimes	9	3.1	3.2	4.9
	Usually	28	9.8	9.8	14.7
	Always	243	84.7	85.3	100.0
	Total	285	99.3	100.0	
Missing	System	2	.7		
	Total	287	100.0		

19. In the last 12 months, how often did your child's CRS doctors or other health providers make it easy for you to discuss your questions or concerns?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	2	.7	.8	.8
	Sometimes	12	4.2	4.6	5.3
	Usually	26	9.1	9.9	15.3
	Always	222	77.4	84.7	100.0
	Total	262	91.3	100.0	
Missing	I didn't have any questions	24	8.4		
	System	1	.3		
	Total	25	8.7		
	Total	287	100.0		

20. In the last 12 months, how often did you have your questions answered by your child's CRS doctors or other health providers?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	3	1.1	1.1	1.1
	Sometimes	13	5.0	5.0	6.1
	Usually	36	13.7	13.8	19.9
	Always	209	79.8	80.1	100.0
	Total	261	99.6	100.0	
Missing	System	1	.4		
	Total	262	100.0		

21. In the last 12 months, how often did you get the specific information you needed from your child's CRS doctors or other health providers?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	5	1.7	2.0	2.0
	Sometimes	18	6.3	7.0	9.0
	Usually	22	7.7	8.6	17.6
	Always	211	73.5	82.4	100.0
	Total	256	89.2	100.0	
Missing	I didn't need any information	27	9.4		
	System	4	1.4		
	Total	31	10.8		
	Total	287	100.0		

22. In the last 12 months, were any decisions about your child's health care made during your CRS visits?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	143	49.8	50.2	50.2
	Yes	142	49.5	49.8	100.0
	Total	285	99.3	100.0	
Missing	System	2	.7		
	Total	287	100.0		

23. When decisions were made in the last 12 months, how often did your child's CRS doctors or other health providers offer you choices about your child's health care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	7	4.9	5.0	5.0
	Sometimes	11	7.7	7.8	12.8
	Usually	21	14.8	14.9	27.7
	Always	102	71.8	72.3	100.0
	Total	141	99.3	100.0	
Missing	System	1	.7		
	Total	142	100.0		

24. When decisions were made in the last 12 months, how often did your child's doctors or other health providers ask you to tell them what choices you prefer?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	15	10.6	10.6	10.6
	Sometimes	6	4.2	4.2	14.8
	Usually	23	16.2	16.2	31.0
	Always	98	69.0	69.0	100.0
	Total	142	100.0	100.0	

25. When decisions were made in the last 12 months, how often did your child's CRS doctors or other health providers involve you as much as you wanted?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	6	4.2	4.2	4.2
	Sometimes	7	4.9	4.9	9.2
	Usually	11	7.7	7.7	16.9
	Always	118	83.1	83.1	100.0
	Total	142	100.0	100.0	

26. What number would you use to rate your child's CRS care in the last 12 months?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 to 3	8	2.8	2.8	2.8
	4 to 7	28	9.8	9.9	12.7
	8 to 10	247	86.1	87.3	100.0
	Total	283	98.6	100.0	
Missing	System	4	1.4		
	Total	287	100.0		

Mean = 8.99, Standard Deviation = 1.72

27. In the last 12 months, did you need an interpreter to help you speak with your child's CRS doctors or other health providers?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid No	No	205	71.4	71.4	71.4
	Yes	82	28.6	28.6	100.0
	Total	287	100.0	100.0	

28. In the last 12 months, when you needed an interpreter to help you speak with your child's CRS doctors or other health providers, how often did you get one?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Sometimes	2	2.4	2.4	2.4
	Usually	4	4.9	4.9	7.3
	Always	76	92.7	92.7	100.0
	Total	82	100.0	100.0	

29. How satisfied were you with the interpreters' assistance?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very Satisfied	35	42.7	42.7	42.7
	Satisfied	44	53.7	53.7	96.3
	Dissatisfied	2	2.4	2.4	98.8
	Very Dissatisfied	1	1.2	1.2	100.0
	Total	82	100.0	100.0	

30. In general, how would you rate your child's overall health now?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Excellent	90	28.7	28.7	28.7
	Very Good	110	35.0	35.0	63.7
	Good	79	25.2	25.2	88.9
	Fair	29	9.2	9.2	98.1
	Poor	6	1.9	1.9	100.0
	Total	314	100.0	100.0	

31. On Oct 1st, the CRS contractor changed to APIPA-CRS. Are you aware of that change?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	50	15.9	16.0	16.0
	Yes	263	83.8	84.0	100.0
	Total	313	99.7	100.0	
Missing	System	1	.3		
	Total	314	100.0		

32. How satisfied are you with the change?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very Satisfied	52	19.8	20.0	20.0
	Satisfied	191	72.6	73.5	93.5
	Dissatisfied	12	4.6	4.6	98.1
	Very Dissatisfied	5	1.9	1.9	100.0
	Total	260	98.9	100.0	
Missing	System	3	1.1		
	Total	263	100.0		

33. Since Oct 1st, there are now more locations where you can get a CRS prescription filled. Are you aware of that change?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	127	40.4	40.8	40.8
	Yes	184	58.6	59.2	100.0
	Total	311	99.0	100.0	
Missing	System	3	1.0		
	Total	314	100.0		

34. Did you know that you can call APIPA-CRS Member Services 24 hours a day, 7 days a week if you have a problem with CRS?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	106	33.8	34.1	34.1
	Yes	205	65.3	65.9	100.0
	Total	311	99.0	100.0	
Missing	System	3	1.0		
	Total	314	100.0		

35. Did you know that you can call the Arizona Department of Health Services, Office for Children with Special Health Care Needs if you have a problem with CRS?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	132	42.0	42.4	42.4
	Yes	179	57.0	57.6	100.0
	Total	311	99.0	100.0	
Missing	System	3	1.0		
	Total	314	100.0		

36. Do you have access to the internet?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	123	39.2	39.2	39.2
	Yes	191	60.8	60.8	100.0
	Total	314	100.0	100.0	

37. Do you have an email account?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	26	13.6	13.7	13.7
	Yes	164	85.9	86.3	100.0
	Total	190	99.5	100.0	
Missing	System	1	.5		
	Total	191	100.0		

38. Is your child of Hispanic or Latino origin or descent?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	114	36.3	38.1	38.1
	Yes	185	58.9	61.9	100.0
	Total	299	95.2	100.0	
Missing	System	15	4.8		
	Total	314	100.0		

39. What is your child's race?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	White	227	72.3	81.4	81.4
	Black	13	4.1	4.7	86.0
	Asian	1	.3	.4	86.4
	Hawaiian/Pacific Islander	2	.6	.7	87.1
	American Indian	19	6.1	6.8	93.9
	Other	11	3.5	3.9	97.8
	Multi-racial	6	1.9	2.2	100.0
	Total	279	88.9	100.0	
Missing	Refused	35	11.1		
Total		314	100.0		

40. What is the highest grade or level of school that you have completed?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	8th Grade or less	32	10.2	10.3	10.3
	Some high school, but did not graduate	47	15.0	15.1	25.3
	High school graduate or GED	92	29.3	29.5	54.8
	Some college or 2-year degree	105	33.4	33.7	88.5
	4-year college graduate	24	7.6	7.7	96.2
	More than 4-year college degree	12	3.8	3.8	100.0
	Total	312	99.4	100.0	
Missing	System	2	.6		
	Total	314	100.0		

41. What language do you mainly speak at home?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	English	181	57.6	57.6	57.6
	Spanish	98	31.2	31.2	88.9
	English & Spanish	30	9.6	9.6	98.4
	Sign Language	1	.3	.3	98.7
	Crean African	1	.3	.3	99.0
	Kordish	1	.3	.3	99.4
	Navajo	1	.3	.3	99.7
	Vietnamese	1	.3	.3	100.0
	Total	314	100.0	100.0	

42. What language does your child mainly speak at home?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	English	183	58.3	59.0	59.0
	Spanish	24	7.6	7.7	66.8
	English & Spanish	75	23.9	24.2	91.0
	Sign Language	9	2.9	2.9	93.9
	Nonverbal	14	4.5	4.5	98.4
	Not Speaking Yet	3	1.0	1.0	99.4
	Crean African	1	.3	.3	99.7
	Kordish	1	.3	.3	100.0
	Total	310	98.7	100.0	
Missing	System	4	1.3		
	Total	314	100.0		

43. How are you related to the child?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Mother or father	278	88.5	89.4	89.4
	Grandparent	17	5.4	5.5	94.9
	Aunt or uncle	2	.6	.6	95.5
	Older brother or sister	1	.3	.3	95.8
	Legal guardian	7	2.2	2.3	98.1
	Self	3	1.0	1.0	99.0
	Someone else	3	1.0	1.0	100.0
	Total	311	99.0	100.0	
Missing	System	3	1.0		
	Total	314	100.0		

APPENDIX D: SURVEY RESPONSES BY SITE

	Question	Phoe	enix	Tuc	son	Flag	staff	Υι	ıma	А	.II
1.	In the last 12 months, did your child see a CRS specialty doctor? Yes No	197 13	93.8% 6.2%	66 3	95.7% 4.3%	13 3	81.3% 18.8%	19 0	100.0% .0%	295 19	93.9% 6.1%
2.	In the past 12 months, did you try to get an appointment with a CRS specialty doctor? Yes No	3 10	23.1% 76.9%	0 3	.0% 100.0%	2 1	66.7% 33.3%	0	.0%	5 14	26.3% 73.7%
3.	In the last 12 months, how much of a problem, if any, was it to see a CRS specialty doctor that your child needed to see? A big problem A small problem Not a problem	13 14 173	6.5% 7.0% 86.5%	3 1 62	4.5% 1.5% 93.9%	2 3 10	13.3% 20.0% 66.7%	0 0 19	.0% .0% 100.0%	18 18 264	6.0% 6.0% 88.0%
4.	What number would you use to rate your child's specialty doctor? Mean ± sd 0 - 3 4 - 7 8 - 10	9.1±1.7 3 23 171	1.5% 11.7% 86.8%	9.4±1.3 1 1 64	1.5% 1.5% 97.0%	8.8±3.0 1 1 1	7.7% 7.7% 84.6%	9.7±0.8 0 1 18	.0% 5.3% 94.7%	9.1±1.7 5 26 264	1.7% 8.8% 89.5%
5.	Did you call the CRS clinic during regular clinic hours to get help or advice for your child? Yes No	88 121	42.1% 57.9%	31 38	44.9% 55.1%	8 8	50.0% 50.0%	6 13	31.6% 68.4%	133 180	42.5% 57.5%
6.	How often did you get the help or advice you needed for your child? Never Sometimes Usually Always	5 13 13 57	5.7% 14.8% 14.8% 64.8%	1 2 3 25	3.2% 6.5% 9.7% 80.6%	1 3 1 3	12.5% 37.5% 12.5% 37.5%	0 0 0 0 6	.0% .0% .0% 100.0%	7 18 17 91	5.3% 13.5% 12.8% 68.4%
7.	When your child needed care right away for their CRS condition, how satisfied were you with how long it took to get care at a CRS clinic? Very Satisfied Satisfied Dissatisfied Very Dissatisfied	32 43 9 4	36.4% 48.9% 10.2% 4.5%	11 28 0 3	26.2% 66.7% .0% 7.1%	7 1 0 2	70.0% 10.0% .0% 20.0%	6 3 0	66.7% 33.3% .0% .0%	56 75 9 9	37.6% 50.3% 6.0% 6.0%

	Question	Pho	enix	Tu	cson	Fla	gstaff	Υι	ıma	4	All
8.	When your child needed care right away for their CRS condition, how long did you have to wait to get care at a CRS clinic? Within 3 days 4 - 7 days More than 7 days Could not get care at clinic	32 8 39 8	36.8% 9.2% 44.8% 9.2%	15 7 17 3	35.7% 16.7% 40.5% 7.1%	3 1 5 1	30.0% 10.0% 50.0% 10.0%	0 0 9 0	.0% .0% 100.0% .0%	50 16 70 12	33.8% 10.8% 47.3% 8.1%
9.	In the last 12 months, how many times did your child go to an emergency room for their CRS condition? None 1 2 3 4 5 to 9 10 or more	159 21 10 7 1 6	76.8% 10.1% 4.8% 3.4% .5% 2.9% 1.4%	58 6 1 1 1 1	84.1% 8.7% 1.4% 1.4% 1.4% 1.4%	13 2 0 0 1 0	81.3% 12.5% .0% .0% 6.3% .0%	15 2 1 0 0 0	83.3% 11.1% 5.6% .0% .0%	245 31 12 8 3 7 4	79.0% 10.0% 3.9% 2.6% 1.0% 2.3% 1.3%
10.	How satisfied were you with how long it took to get an appointment at a CRS clinic? Very Satisfied Satisfied Dissatisfied Very Dissatisfied	47 69 16 11	32.9% 48.3% 11.2% 7.7%	24 33 2 2	39.3% 54.1% 3.3% 3.3%	4 9 1 2	25.0% 56.3% 6.3% 12.5%	7 8 1 0	43.8% 50.0% 6.3% .0%	82 119 20 15	34.7% 50.4% 8.5% 6.4%
11.	When you called to schedule an appointment for your child at the CRS clinic, most of the time, how long did you have to wait for an appointment? 45 days or less 46 to 90 days More than 90 days Could not get an appt	88 13 24 15	62.9% 9.3% 17.1% 10.7%	41 3 15 2	67.2% 4.9% 24.6% 3.3%	9 3 2 2	56.3% 18.8% 12.5% 12.5%	10 0 4 2	62.5% .0% 25.0% 12.5%	148 19 45 21	63.5% 8.2% 19.3% 9.0%
12.	Not counting the times your child went to an emergency room, how many times did your child go to the CRS clinic? None 1 2 3 4 5 to 9 10 or more	18 50 45 21 19 34 23	8.6% 23.8% 21.4% 10.0% 9.0% 16.2% 11.0%	5 12 13 13 6 13 7	7.2% 17.4% 18.8% 18.8% 8.7% 18.8% 10.1%	3 5 4 2 1 1 0	18.8% 31.3% 25.0% 12.5% 6.3% 6.3%	1 7 5 2 3 1 0	5.3% 36.8% 26.3% 10.5% 15.8% 5.3% .0%	27 74 67 38 29 49 30	8.6% 23.6% 21.3% 12.1% 9.2% 15.6% 9.6%

	Question	Pho	enix	Tuc	son	Flag	staff	Yu	ma	All	
13.	In the last 12 months, when you had an appointment at the CRS clinic, how long after your appointment time, did your child have to wait to be taken to the exam room? Less than 15 minutes 15-30 minutes 31-45 minutes 46-60 minutes More than an hour	89 69 16 10 8	46.4% 35.9% 8.3% 5.2% 4.2%	42 18 0 2 2	65.6% 28.1% .0% 3.1% 3.1%	8 4 0 0	61.5% 30.8% .0% .0% 7.7%	6 8 3 1	33.3% 44.4% 16.7% 5.6% .0%	145 99 19 13 11	50.5% 34.5% 6.6% 4.5% 3.8%
14.	How often did office staff at your child's CRS clinic treat you and your child with courtesy and respect? Never Sometimes Usually Always	0 4 5 183	.0% 2.1% 2.6% 95.3%	1 2 0 61	1.6% 3.1% .0% 95.3%	1 0 1	7.7% .0% 7.7% 84.6%	0 0 0 18	.0% .0% .0% 100.0%	2 6 6 273	.7% 2.1% 2.1% 95.1%
15.	How often were office staff at your child's CRS clinic as helpful as you thought they should be? Never Sometimes Usually Always	2 9 21 159	1.0% 4.7% 11.0% 83.2%	1 3 1 59	1.6% 4.7% 1.6% 92.2%	1 0 0	7.7% .0% .0% 92.3%	0 0 1 17	.0% .0% 5.6% 94.4%	4 12 23 247	1.4% 4.2% 8.0% 86.4%
16.	How often did the CRS clinic staff listen carefully to you? Never Sometimes Usually Always	2 6 20 163	1.0% 3.1% 10.5% 85.3%	1 3 3 55	1.6% 4.8% 4.8% 88.7%	1 0 1 11	7.7% .0% 7.7% 84.6%	0 0 1 16	.0% .0% 5.9% 94.1%	4 9 25 245	1.4% 3.2% 8.8% 86.6%
17.	How often did your child's CRS doctors or other health providers explain things in a way you could understand? Never Sometimes Usually Always	0 8 23 160	.0% 4.2% 12.0% 83.8%	0 4 3 57	.0% 6.3% 4.7% 89.1%	1 0 2 10	7.7% .0% 15.4% 76.9%	0 0 2 16	.0% .0% 11.1% 88.9%	1 12 30 243	.3% 4.2% 10.5% 85.0%

	Question	Pho	enix	Tuc	Tucson Flagstaff		Yu	ma	All		
18.	How often did your child's CRS doctors or other health providers show respect for what you had to say? Never Sometimes Usually Always	3 8 22 158	1.6% 4.2% 11.5% 82.7%	1 1 5 56	1.6% 1.6% 7.9% 88.9%	1 0 0	7.7% .0% .0% 92.3%	0 0 1 17	.0% .0% 5.6% 94.4%	5 9 28 243	1.8% 3.2% 9.8% 85.3%
19.	How often did your child's CRS doctors or other health providers make it easy for you to discuss your questions or concerns? Never Sometimes Usually Always	1 8 22 143	.6% 4.6% 12.6% 82.2%	0 3 1 55	.0% 5.1% 1.7% 93.2%	1 0 0	7.7% .0% .0% 92.3%	0 1 3 12	.0% 6.3% 18.8% 75.0%	2 12 26 222	.8% 4.6% 9.9% 84.7%
20.	How often did you have your questions answered by your child's CRS doctors or other health providers? Never Sometimes Usually Always	1 10 26 136	.6% 5.8% 15.0% 78.6%	0 2 5 52	.0% 3.4% 8.5% 88.1%	1 1 2 9	7.7% 7.7% 15.4% 69.2%	1 0 3 12	6.3% .0% 18.8% 75.0%	3 13 36 209	1.1% 5.0% 13.8% 80.1%
21.	How often did you get the specific information you needed from your child's CRS doctors or other health providers? Never Sometimes Usually Always	3 12 17 135	1.8% 7.2% 10.2% 80.8%	1 3 1 54	1.7% 5.1% 1.7% 91.5%	1 2 2 8	7.7% 15.4% 15.4% 61.5%	0 1 2 14	.0% 5.9% 11.8% 82.4%	5 18 22 211	2.0% 7.0% 8.6% 82.4%
22.	Were any decisions about your child's health care made during your CRS visits? Yes No	95 95	50.0% 50.0%	32 32	50.0% 50.0%	7 6	53.8% 46.2%	8	44.4% 55.6%	142 143	49.8% 50.2%

	Question	Pho	enix	Tuc	cson	Flag	gstaff	Υι	ıma	F	All
23.	When decisions were made, how often did your child's CRS doctors or other health providers offer you choices about your child's health care? Never Sometimes Usually Always	5 8 11 71	5.3% 8.4% 11.6% 74.7%	2 2 7 21	6.3% 6.3% 21.9% 65.6%	0 1 2 4	.0% 14.3% 28.6% 57.1%	0 0 1 6	.0% .0% 14.3% 85.7%	7 11 21 102	5.0% 7.8% 14.9% 72.3%
24.	When decisions were made, how often did your child's doctors or other health providers ask you to tell them what choices you prefer? Never Sometimes Usually Always	9 6 14 66	9.5% 6.3% 14.7% 69.5%	4 0 5 23	12.5% .0% 15.6% 71.9%	1 0 3 3	14.3% .0% 42.9% 42.9%	1 0 1 6	12.5% .0% 12.5% 75.0%	15 6 23 98	10.6% 4.2% 16.2% 69.0%
25.	When decisions were made, how often did your child's CRS doctors or other health providers involve you as much as you wanted? Never Sometimes Usually Always	5 6 5 79	5.3% 6.3% 5.3% 83.2%	1 0 3 28	3.1% .0% 9.4% 87.5%	0 0 3 4	.0% .0% 42.9% 57.1%	0 1 0 7	.0% 12.5% .0% 87.5%	6 7 11 118	4.2% 4.9% 7.7% 83.1%
26.	What number would you use to rate your child's CRS care in the last 12 months? Mean ± sd 0 - 3 4 - 7 8 - 10	8.9±1.7 4 25 160	2.1% 13.2% 84.7%	9.2±1.6 2 2 60	3.1% 3.1% 93.8%	8.9±2.8 1 1	7.7% 7.7% 84.6%	9.5±1.9 1 0 16	5.9% .0% 94.1%	9.0±1.7 8 28 247	2.8% 9.9% 87.3%
27.	Did you need an interpreter to help you speak with your child's CRS doctors or other health providers? Yes No	63 129	32.8% 67.2%	11 53	17.2% 82.8%	2 11	15.4% 84.6%	6 12	33.3% 66.7%	82 205	28.6% 71.4%
28.	When you needed an interpreter, how often did you get one? Sometimes Usually Always	2 3 58	3.2% 4.8% 92.1%	0 1 10	.0% 9.1% 90.9%	0 0 2	.0% .0% 100.0%	0 0 6	.0% .0% 100.0%	2 4 76	2.4% 4.9% 92.7%

	Question	Phoenix Tu		Tuc	ucson Flagstaff		staff	Yuma		All	
29.	How satisfied were you with the interpreters' assistance? Very Satisfied Satisfied Dissatisfied Very Dissatisfied	25 35 2 1	39.7% 55.6% 3.2% 1.6%	5 6 0	45.5% 54.5% .0% .0%	1 1 0 0	50.0% 50.0% .0% .0%	4 2 0 0	66.7% 33.3% .0%	35 44 2 1	42.7% 53.7% 2.4% 1.2%
30.	How would you rate your child's overall health now? Excellent Very Good Good Fair Poor	56 67 58 23 6	26.7% 31.9% 27.6% 11.0% 2.9%	24 31 11 3 0	34.8% 44.9% 15.9% 4.3%	6 2 5 3 0	37.5% 12.5% 31.3% 18.8% .0%	4 10 5 0	21.1% 52.6% 26.3% .0%	90 110 79 29 6	28.7% 35.0% 25.2% 9.2% 1.9%
31.	On Oct 1st, the CRS contractor changed to APIPA- CRS. Are you aware of that change? Yes No	180 29	86.1% 13.9%	54 15	78.3% 21.7%	12 4	75.0% 25.0%	17 2	89.5% 10.5%	263 50	84.0% 16.0%
32.	How satisfied are you with the change? Very Satisfied Satisfied Dissatisfied Very Dissatisfied	35 129 9 4	19.8% 72.9% 5.1% 2.3%	12 40 2 0	22.2% 74.1% 3.7% .0%	1 10 1 0	8.3% 83.3% 8.3% .0%	4 12 0 1	23.5% 70.6% .0% 5.9%	52 191 12 5	20.0% 73.5% 4.6% 1.9%
33.	Since Oct 1st, there are now more locations where you can get a CRS prescription filled. Are you aware of that change? Yes No	119 89	57.2% 42.8%	46 22	67.6% 32.4%	8 8	50.0% 50.0%	11 8	57.9% 42.1%	184 127	59.2% 40.8%
34.	Did you know that you can call APIPA-CRS Member Services if you have a problem with CRS? Yes No	131 76	63.3% 36.7%	47 22	68.1% 31.9%	12 4	75.0% 25.0%	15 4	78.9% 21.1%	205 106	65.9% 34.1%
35.	Did you know that you can call the Arizona Department of Health Services, Office for Children with Special Health Care Needs if you have a problem with CRS?	107	51.7%	49	71.0%	9	56.3%	14	73.7%	179	57.6%
	No	100	48.3%	20	29.0%	7	43.8%	5	26.3%	132	42.4%

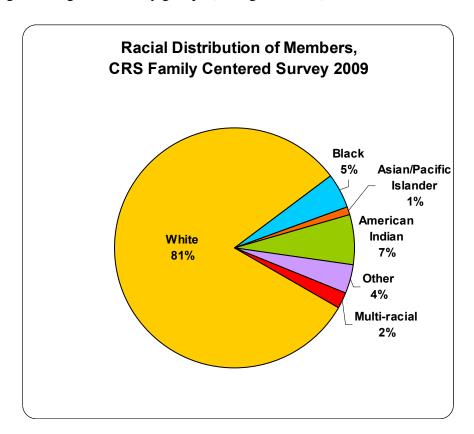
	Question	Pho	enix	Tuc	son	Flagstaff		Yuma		All	
36.	Do you have access to the internet? Yes No	127 83	60.5% 39.5%	46 23	66.7% 33.3%	9 7	56.3% 43.8%	9 10	47.4% 52.6%	191 123	60.8% 39.2%
37.	Do you have an email account? Yes No	111 16	87.4% 12.6%	38 8	82.6% 17.4%	7 2	77.8% 22.2%	8	88.9% 11.1%	164 27	85.9% 14.1%
38.	Is your child of Hispanic or Latino origin or descent? Yes No	125 80	61.0% 39.0%	38 27	58.5% 41.5%	5 7	41.7% 58.3%	17 0	100.0% .0%	185 114	61.9% 38.1%
39.	What is your child's race? White Black Asian Hawaiian/Pacific Islander American Indian Other Multi-racial Refused to answer	166 11 1 0 8 7 3	79.0% 5.2% .5% .0% 3.8% 3.3% 1.4% 6.7%	40 2 0 1 6 2 2	58.0% 2.9% .0% 1.4% 8.7% 2.9% 2.9% 23.2%	8 0 0 1 5 0	50.0% .0% .0% 6.3% 31.3% .0% 6.3%	13 0 0 0 0 0 2 0 4	68.4% .0% .0% .0% .0% 10.5% .0% 21.1%	227 13 1 2 19 11 6 35	72.3% 4.1% .3% .6% 6.1% 3.5% 1.9% 11.1%
40.	What is the highest grade or level of school that you have completed? 8 th grade or less Some high school High school grad or GED Some coll. or 2-yr deg. 4-yr college graduate More than 4-yr coll. deg.	24 34 61 64 16	11.5% 16.3% 29.2% 30.6% 7.7% 4.8%	4 8 18 31 6 2	5.8% 11.6% 26.1% 44.9% 8.7% 2.9%	0 2 8 5 1	.0% 12.5% 50.0% 31.3% 6.3% .0%	4 3 5 5 1 0	22.2% 16.7% 27.8% 27.8% 5.6%	32 47 92 105 24	10.3% 15.1% 29.5% 33.7% 7.7% 3.8%
41.	What language do you mainly speak at home? English Spanish English & Spanish Sign Language Crean African Kordish Navajo Vietnamese	116 72 19 1 0 1	55.2% 34.3% 9.0% .5% .0% .5%	43 16 9 0 1 0 0	62.3% 23.2% 13.0% .0% 1.4% .0% .0%	14 1 0 0 0 0	87.5% 6.3% .0% .0% .0% .0% 6.3%	8 9 2 0 0 0 0	42.1% 47.4% 10.5% .0% .0% .0%	181 98 30 1 1 1	57.6% 31.2% 9.6% .3% .3% .3% .3%

	Question	Pho	enix	Tuc	son	Flag	ıstaff	Yu	ma	All	
42.	What language does your child mainly speak at home?										
	English	116	55.8%	46	67.6%	14	87.5%	7	38.9%	183	59.0%
	Spanish	15	7.2%	5	7.4%	1	6.3%	3	16.7%	24	7.7%
	English & Spanish	54	26.0%	14	20.6%	1	6.3%	6	33.3%	75	24.2%
	Sign language	8	3.8%	0	.0%	0	.0%	1	5.6%	9	2.9%
	Nonverbal	11	5.3%	2	2.9%	0	.0%	1	5.6%	14	4.5%
	Not speaking yet	3	1.4%	0	.0%	0	.0%	0	.0%	3	1.0%
	Crean African	0	.0%	1	1.5%	0	.0%	0	.0%	1	.3%
	Kordish	1	.5%	0	.0%	0	.0%	0	.0%	1	.3%
43.	How are you related to the child?										
	Mother or father	188	90.0%	59	86.8%	14	93.3%	17	89.5%	278	89.4%
	Grandparent	12	5.7%	4	5.9%	0	.0%	1	5.3%	17	5.5%
	Aunt or uncle	2	1.0%	0	.0%	0	.0%	0	.0%	2	.6%
	Older brother or sister	0	.0%	1	1.5%	0	.0%	0	.0%	1	.3%
	Legal guardian	3	1.4%	2	2.9%	1	6.7%	1	5.3%	7	2.3%
	Self	3	1.4%	0	.0%	0	.0%	0	.0%	3	1.0%
	Someone else	1	.5%	2	2.9%	0	.0%	0	.0%	3	1.0%

APPENDIX E: CULTURAL COMPETENCY EVALUATION

Culture can be defined as a shared, learned symbolic system of values, beliefs and attitudes that shape and influence perception and behavior. Culture is often taken for granted because it seems so natural and normal. Language is an important component of culture as is food, music, and religion. Culture is learned through social interaction and is most apparent when one violates taken-for-granted rules. Although culture is not directly observable, one can see its effects through behavior.

CRS serves many children who come from diverse cultural backgrounds. In the 2009 Family Centered Survey, it was estimated that 62 percent of CRS members represented by respondents were of Hispanic origin. As for the racial distribution, 81 percent of the members were White (includes Hispanic and Non-Hispanic) with the remaining members belonging to a range of minority groups (see figure below).

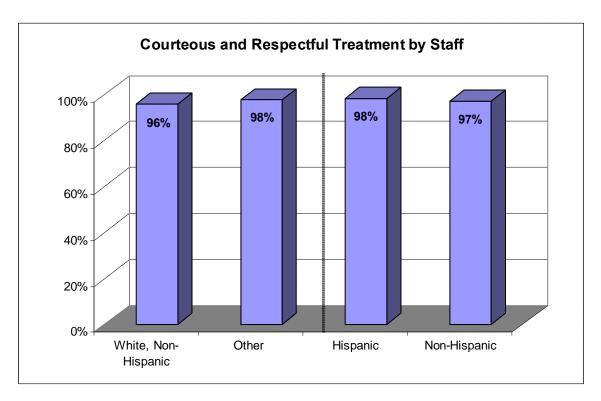


Cultural competency of CRS continues to be evaluated through the Family Centered Survey. The telephone survey included seven questions which directly related to cultural competency and five questions that were indirectly related. One way of assessing cultural competency is to evaluate differences between racial/ethnic groups. Results to each question were tabulated in order to compare White, Non-Hispanic members to those who are minorities, and Hispanic members to Non-Hispanic members. Comparisons to other races (Black, Asian/Pacific Islander, and American Indian) could not be made due to the small number of respondents within each group. Over-sampling may need to be performed in the future to obtain estimates for all races.

Among the results of the directly and indirectly related questions, no statistical differences were found between Hispanic and Non-Hispanic members or between White, Non-Hispanics and other minorities. Tables showing detailed results are included at the end of the document.

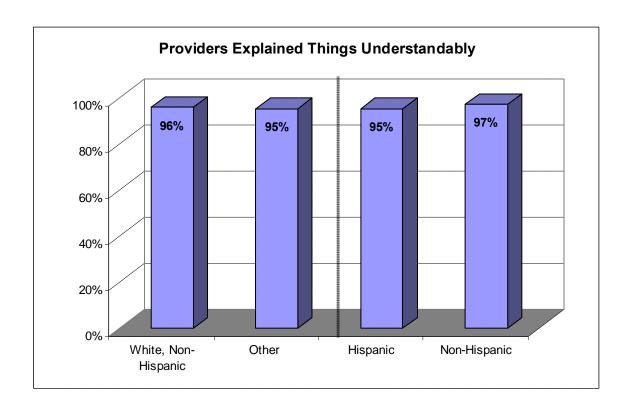
RESULTS (QUESTIONS DIRECTLY RELATED TO CULTURAL COMPETENCY)

Question 1: In the last 12 months, how often did office staff at your child & CRS clinic treat you and your child with courtesy and respect?



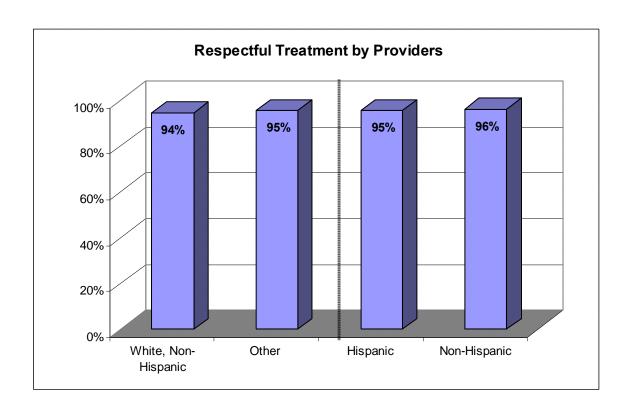
• In 2009, the vast majority of respondents in all four racial/ethnic groups reported that they were usually or always treated with courtesy and respect by the CRS staff. No significant differences were found between Whites and minorities or between Hispanics and Non-Hispanics. The outcomes for this question were not statistically different from the outcomes in 2008.

Question 2: In the last 12 months, how often did your child¢s CRS doctors or other health providers explain things in a way you could understand?



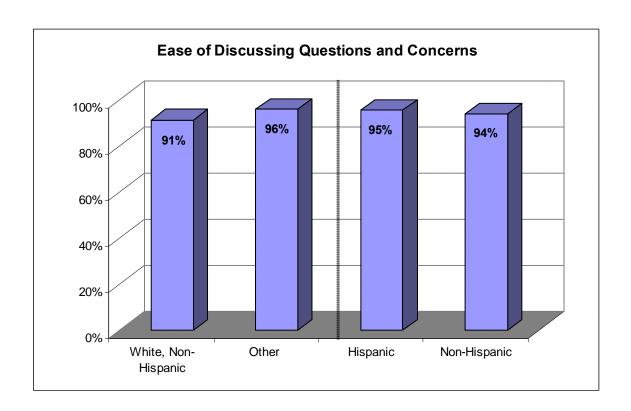
• A high percentage of respondents reported that CRS doctors and other health providers usually or always explained things understandably. No significant differences were found between Whites and minorities or between Hispanics and Non-Hispanics. The results of this question were not statistically different from the 2008 results.

Question 3: In the last 12 months, how often did your childøs CRS doctors or other health providers show respect for what you had to say?



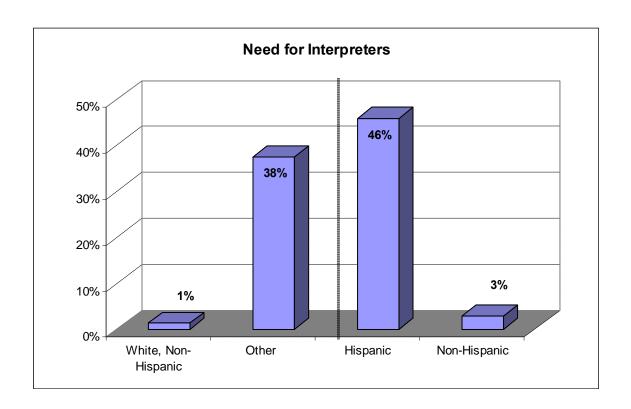
• In 2009, providers continued to show respect for what families had to say. Ninety-five percent of both Hispanic and minority families reported that they were usually or always treated with respect by CRS doctors and other health providers. No significant differences were found between Whites and minorities or between Hispanics and Non-Hispanics. The outcomes for this question were not statistically different from the outcomes in 2008.

Question 4: In the last 12 months, how often did your child¢s CRS doctors or other health providers make it easy for you to discuss your questions or concerns?



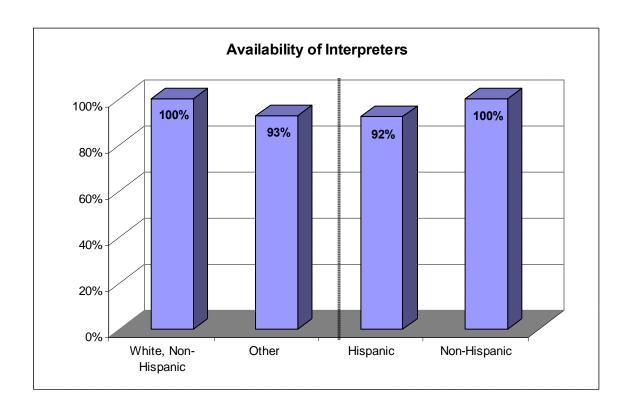
Over 90 percent of member families contacted through the survey reported that it
was usually or always easy to discuss their questions and concerns with providers.
No significant differences were found between Whites and minorities or between
Hispanics and Non-Hispanics. The results of this question were not statistically
different from the 2008 results.

Question 5: In the last 12 months, did you need an interpreter to help you speak with your child¢s CRS doctors or other health providers?



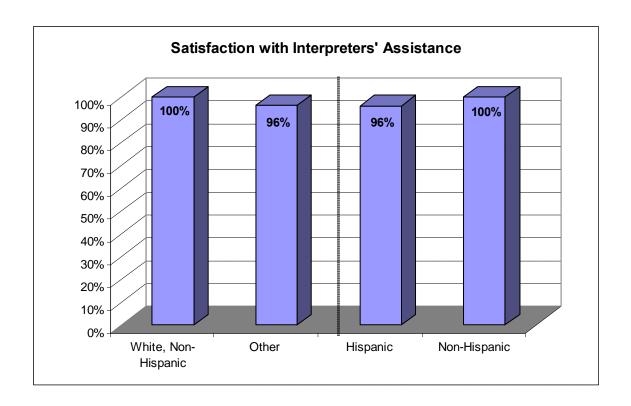
• Very few White and Non-Hispanic members needed an interpreter to assist them. However, almost half of Hispanic respondents (46%) needed an interpreter within the past year along with 38 percent of minority families.

Question 6: In the last 12 months, when you needed an interpreter to help you speak with your child & CRS doctors or other health providers, how often did you get one?



• Due to the small number of members who actually needed an interpreter, statistical differences between the racial/ethnic groups could not be concluded. Only a few White and Non-Hispanic respondents needed an interpreter but were always accommodated. The majority of minority families (93%) indicated that an interpreter was always available to them and 92 percent of Hispanic families reported likewise.

Question 7: How satisfied were you with the interpretersøassistance?



• This is one of eight new questions that were added to the Family Centered Survey in 2009. Satisfaction of interpreters was very positive. Ninety-six percent of both Hispanic and minority families were satisfied or very satisfied with the interpretersøassistance.

Results to Questions Indirectly Related to Cultural Competency

Table 1. Helpful Staff vs. Ethnicity

	-		Hisp	anic	
			No	Yes	Total
In the last 12 months, how	Never	Count	1	2	3
often were office staff at your childs CRS clinic as		% within Hispanic	1.0%	1.2%	1.1%
helpful as you thought they	Sometimes	Count	3	8	11
should be?		% within Hispanic	2.9%	4.7%	4.0%
	Usually	Count	11	10	21
		% within Hispanic	10.8%	5.9%	7.7%
	Always	Count	87	150	237
		% within Hispanic	85.3%	88.2%	87.1%
Total	•	Count	102	170	272
		% within Hispanic	100.0%	100.0%	100.0%

Table 2. Listens vs. Ethnicity

			Hisp	anic	
			No	Yes	Total
In the last 12 months, how	Never	Count	1	2	3
often did the CRS clinic staff listen carefully to you?		% within Hispanic	1.0%	1.2%	1.1%
otali liotori odroraliy to you.	Sometimes	Count	4	4	8
		% within Hispanic	3.9%	2.4%	3.0%
	Usually	Count	13	10	23
		% within Hispanic	12.7%	5.9%	8.5%
	Always	Count	84	153	237
		% within Hispanic	82.4%	90.5%	87.5%
Total		Count	102	169	271
		% within Hispanic	100.0%	100.0%	100.0%

Table 3. Providers Answer Questions vs. Ethnicity

	-	-	Hispanic		
			No	Yes	Total
In the last 12 months, how	Never	Count	1	1	2
often did you have your questions answered by		% within Hispanic	1.0%	.7%	.8%
your childs CRS doctors or	Sometimes	Count	5	8	13
other health providers?		% within Hispanic	5.2%	5.3%	5.2%
	Usually	Count	14	18	32
		% within Hispanic	14.4%	11.9%	12.9%
	Always	Count	77	124	201
		% within Hispanic	79.4%	82.1%	81.0%
Total		Count	97	151	248
		% within Hispanic	100.0%	100.0%	100.0%

Table 4. Providers Give Information vs. Ethnicity

			Hispanic		
			No	Yes	Total
In the last 12 months, how	Never	Count	3	1	4
often did you get the specific information you		% within Hispanic	3.2%	.7%	1.7%
needed from your childas	Sometimes	Count	5	12	17
CRS doctors or other health providers?		% within Hispanic	5.4%	8.1%	7.0%
noam providoro.	Usually	Count	9	9	18
		% within Hispanic	9.7%	6.0%	7.4%
	Always	Count	76	127	203
		% within Hispanic	81.7%	85.2%	83.9%
Total		Count	93	149	242
		% within Hispanic	100.0%	100.0%	100.0%

Table 5. Providers Offer Choices vs. Ethnicity

			Hisp	anic	
			No	Yes	Total
When decisions were	Never	Count	4	3	7
made in the last 12 months, how often did your		% within Hispanic	7.5%	3.8%	5.3%
childs CRS doctors or	Sometimes	Count	4	6	10
other health providers offer you choices about your		% within Hispanic	7.5%	7.7%	7.6%
childs health care?	Usually	Count	9	10	19
		% within Hispanic	17.0%	12.8%	14.5%
	Always	Count	36	59	95
		% within Hispanic	67.9%	75.6%	72.5%
Total	•	Count	53	78	131
		% within Hispanic	100.0%	100.0%	100.0%

Table 6. Helpful Staff, White vs. Other

			White vs. Other		
			Other	White, Non- Hispanic	Total
In the last 12 months, how	Never	Count	3	1	4
often were office staff at your childs CRS clinic as helpful		% within White vs. Other	1.4%	1.4%	1.4%
as you thought they should	Sometimes	Count	9	3	12
be?		% within White vs. Other	4.2%	4.3%	4.2%
	Usually	Count	17	6	23
		% within White vs. Other	7.9%	8.6%	8.0%
	Always	Count	187	60	247
		% within White vs. Other	86.6%	85.7%	86.4%
Total		Count	216	70	286
		% within White vs. Other	100.0%	100.0%	100.0%

Table 7. Staff Listens, White vs. Other

	-	-	White vs. Other		
			Other	White, Non- Hispanic	Total
In the last 12 months, how	Never	Count	3	1	4
often did the CRS clinic staff listen carefully to you?		% within White vs. Other	1.4%	1.4%	1.4%
insterr carefully to you!	Sometimes	Count	5	4	9
		% within White vs. Other	2.3%	5.7%	3.2%
	Usually	Count	16	9	25
		% within White vs. Other	7.5%	12.9%	8.8%
	Always	Count	189	56	245
		% within White vs. Other	88.7%	80.0%	86.6%
Total		Count	213	70	283
		% within White vs. Other	100.0%	100.0%	100.0%

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Table 8. Providers Answer Questions, White vs. Other

	-	-	White vs. Other		
			Other	White, Non- Hispanic	Total
In the last 12 months, how	Never	Count	2	1	3
often did you have your questions answered by your		% within White vs. Other	1.0%	1.5%	1.1%
childes CRS doctors or other	Sometimes	Count	9	4	13
health providers?		% within White vs. Other	4.7%	5.9%	5.0%
	Usually	Count	25	11	36
		% within White vs. Other	13.0%	16.2%	13.8%
	Always	Count	157	52	209
		% within White vs. Other	81.3%	76.5%	80.1%
Total		Count	193	68	261
		% within White vs. Other	100.0%	100.0%	100.0%

Table 9. Providers Give Information, White vs. Other

	-	-	White vs. Other		
			Other	White, Non- Hispanic	Total
In the last 12 months, how	Never	Count	2	3	5
often did you get the specific information you needed from		% within White vs. Other	1.0%	4.7%	2.0%
your childes CRS doctors or	Sometimes	Count	14	4	18
other health providers?		% within White vs. Other	7.3%	6.3%	7.0%
	Usually	Count	13	9	22
		% within White vs. Other	6.8%	14.1%	8.6%
	Always	Count	163	48	211
		% within White vs. Other	84.9%	75.0%	82.4%
Total		Count	192	64	256
		% within White vs. Other	100.0%	100.0%	100.0%

Table 10. Providers Offer Choices, White vs. Other

		-	White vs. Other		
			Other	White, Non- Hispanic	Total
When decisions were made	Never	Count	4	3	7
in the last 12 months, how often did your childs CRS		% within White vs. Other	4.0%	7.5%	5.0%
doctors or other health	Sometimes	Count	8	3	11
providers offer you choices about your childs health		% within White vs. Other	7.9%	7.5%	7.8%
care?	Usually	Count	15	6	21
		% within White vs. Other	14.9%	15.0%	14.9%
	Always	Count	74	28	102
		% within White vs. Other	73.3%	70.0%	72.3%
Total	•	Count	101	40	141
		% within White vs. Other	100.0%	100.0%	100.0%

Results to Questions Directly Related to Cultural Competency

Table 11. Courteous and Respectful Treatment by Staff vs. Ethnicity

			Hispanic		
			No	Yes	Total
In the last 12 months, how	Never	Count	1	0	1
often did office staff at your childs CRS clinic treat you		% within Hispanic	1.0%	.0%	.4%
and your child with	Sometimes	Count	2	3	5
courtesy and respect?		% within Hispanic	1.9%	1.8%	1.8%
	Usually	Count	3	3	6
		% within Hispanic	2.9%	1.8%	2.2%
	Always	Count	97	164	261
		% within Hispanic	94.2%	96.5%	95.6%
Total		Count	103	170	273
		% within Hispanic	100.0%	100.0%	100.0%

Table 12. Ease of Discussing Questions and Concerns vs. Ethnicity

	-	-	Hisp	anic	
			No	Yes	Total
In the last 12 months, how	Never	Count	1	0	1
often did your childs CRS doctors or other health		% within Hispanic	1.0%	.0%	.4%
providers make it easy for	Sometimes	Count	5	7	12
you to discuss your questions or concerns?		% within Hispanic	5.2%	4.6%	4.8%
quodione of concerns.	Usually	Count	11	12	23
		% within Hispanic	11.3%	7.9%	9.2%
	Always	Count	80	133	213
		% within Hispanic	82.5%	87.5%	85.5%
Total		Count	97	152	249
		% within Hispanic	100.0%	100.0%	100.0%

Table 13. Understanding Providers vs. Ethnicity

			Hispanic		
			No	Yes	Total
In the last 12 months, how often did your childs CRS doctors or other health	Sometimes	Count	3	8	11
		% within Hispanic	2.9%	4.7%	4.0%
providers explain things in	Usually	Count	10	15	25
a way you could understand?		% within Hispanic	9.7%	8.9%	9.2%
	Always	Count	90	146	236
		% within Hispanic	87.4%	86.4%	86.8%
Total	•	Count	103	169	272
		% within Hispanic	100.0%	100.0%	100.0%

Table14. Respectful Treatment by Providers vs. Ethnicity

			Hisp		
			No	Yes	Total
In the last 12 months, how	Never	Count	2	2	4
often did your childs CRS doctors or other health		% within Hispanic	2.0%	1.2%	1.5%
providers show respect for	Sometimes	Count	2	6	8
what you had to say?		% within Hispanic	2.0%	3.6%	3.0%
	Usually	Count	13	12	25
		% within Hispanic	12.7%	7.1%	9.2%
	Always	Count	85	149	234
		% within Hispanic	83.3%	88.2%	86.3%
Total		Count	102	169	271
		% within Hispanic	100.0%	100.0%	100.0%

Table 15. Need for Interpreters vs. Ethnicity

	=	_	Hisp		
			No	Yes	Total
In the last 12 months, did you need an interpreter to help you speak with your childes CRS doctors or other health providers?	No	Count	100	92	192
		% within Hispanic	97.1%	54.1%	70.3%
	Yes	Count	3	78	81
		% within Hispanic	2.9%	45.9%	29.7%
Total		Count	103	170	273
		% within Hispanic	100.0%	100.0%	100.0%

Table16. Availability of Interpreters vs. Ethnicity

	=	-	Hispanic		
			No	Yes	Total
In the last 12 months, when	Sometimes	Count	0	2	2
you needed an interpreter to help you speak with your		% within Hispanic	.0%	2.6%	2.5%
childs CRS doctors or	Usually	Count	0	4	4
other health providers, how often did you get one?		% within Hispanic	.0%	5.1%	4.9%
oner did you get one:	Always	Count	3	72	75
		% within Hispanic	100.0%	92.3%	92.6%
Total		Count	3	78	81
		% within Hispanic	100.0%	100.0%	100.0%

Table 17. Satisfaction with Interpreters' Assistance by Ethnicity

	<u>-</u>	-	Hisp	Hispanic	
			No	Yes	Total
How satisfied were you	Very Satisfied	Count	2	32	34
with the interpreters' assistance?		% within Hispanic	66.7%	41.0%	42.0%
assistance?	Satisfied	Count	1	43	44
		% within Hispanic	33.3%	55.1%	54.3%
	Dissatisfied	Count	0	2	2
		% within Hispanic	.0%	2.6%	2.5%
	Very Dissatisfied	Count	0	1	1
		% within Hispanic	.0%	1.3%	1.2%
Total		Count	3	78	81
		% within Hispanic	100.0%	100.0%	100.0%

Table 18. Courteous and Respectful Treatment by Staff, White vs. Other

		-	White vs. Other		
			Other	White, Non- Hispanic	Total
In the last 12 months, how	Never	Count	1	1	2
often did office staff at your childs CRS clinic treat you		% within White vs. Other	.5%	1.4%	.7%
and your child with courtesy	Sometimes	Count	4	2	6
and respect?		% within White vs. Other	1.9%	2.8%	2.1%
	Usually	Count	5	1	6
		% within White vs. Other	2.3%	1.4%	2.1%
	Always	Count	206	67	273
		% within White vs. Other	95.4%	94.4%	95.1%
Total		Count	216	71	287
		% within White vs. Other	100.0%	100.0%	100.0%

Table 19. Ease of Discussing Questions and Concerns, White vs. Other

	-	-	White vs. Other		
			Other	White, Non- Hispanic	Total
In the last 12 months, how	Never	Count	1	1	2
often did your childs CRS doctors or other health		% within White vs. Other	.5%	1.5%	.8%
providers make it easy for	Sometimes	Count	7	5	12
you to discuss your questions or concerns?		% within White vs. Other	3.6%	7.4%	4.6%
questions of concerns:	Usually	Count	16	10	26
		% within White vs. Other	8.2%	14.7%	9.9%
	Always	Count	170	52	222
		% within White vs. Other	87.6%	76.5%	84.7%
Total		Count	194	68	262
		% within White vs. Other	100.0%	100.0%	100.0%

Table 20. Understanding Providers, White vs. Other

	_	-	White	e vs. Other	
			Other	White, Non- Hispanic	Total
In the last 12 months, how	Never	Count	1	0	1
often did your childs CRS doctors or other health		% within White vs. Other	.5%	.0%	.3%
providers explain things in a	Sometimes	Count	9	3	12
way you could understand?		% within White vs. Other	4.2%	4.2%	4.2%
	Usually	Count	22	8	30
		% within White vs. Other	10.2%	11.3%	10.5%
	Always	Count	183	60	243
		% within White vs. Other	85.1%	84.5%	85.0%
Total		Count	215	71	286
		% within White vs. Other	100.0%	100.0%	100.0%

Table 21. Respectful Treatment by Providers, White vs. Other

	-	-	White	vs. Other	
			Other	White, Non- Hispanic	Total
In the last 12 months, how	Never	Count	3	2	5
often did your childs CRS doctors or other health		% within White vs. Other	1.4%	2.8%	1.8%
providers show respect for	Sometimes	Count	7	2	9
what you had to say?		% within White vs. Other	3.3%	2.8%	3.2%
	Usually	Count	17	11	28
		% within White vs. Other	7.9%	15.5%	9.8%
	Always	Count	187	56	243
		% within White vs. Other	87.4%	78.9%	85.3%
Total		Count	214	71	285
		% within White vs. Other	100.0%	100.0%	100.0%

Table 22. Need for Interpreters, White vs. Other

			White vs. Other		
			Other	White, Non- Hispanic	Total
In the last 12 months, did you need an interpreter to help you speak with your childos CRS doctors or other health providers?	No	Count	135	70	205
		% within White vs. Other	62.5%	98.6%	71.4%
	Yes	Count	81	1	82
		% within White vs. Other	37.5%	1.4%	28.6%
Total		Count	216	71	287
		% within White vs. Other	100.0%	100.0%	100.0%

Table 23. Availability of Interpreters, White vs. Other

			White	White vs. Other	
			Other	White, Non- Hispanic	Total
In the last 12 months, when	Sometimes	Count	2	0	2
you needed an interpreter to help you speak with your		% within White vs. Other	2.5%	.0%	2.4%
childs CRS doctors or other	Usually	Count	4	0	4
health providers, how often did you get one?		% within White vs. Other	4.9%	.0%	4.9%
did you get one:	Always	Count	75	1	76
		% within White vs. Other	92.6%	100.0%	92.7%
Total		Count	81	1	82
		% within White vs. Other	100.0%	100.0%	100.0%

Table 24. Satisfaction with Interpreters' Assistance, White vs. Other

	_		White	vs. Other	
			Other	White, Non- Hispanic	Total
How satisfied were you with	Very Satisfied	Count	34	1	35
the interpreters' assistance?		% within White vs. Other	42.0%	100.0%	42.7%
	Satisfied	Count	44	0	44
		% within White vs. Other	54.3%	.0%	53.7%
	Dissatisfied	Count	2	0	2
		% within White vs. Other	2.5%	.0%	2.4%
	Very Dissatisfied	Count	1	0	1
		% within White vs. Other	1.2%	.0%	1.2%
Total		Count	81	1	82
		% within White vs. Other	100.0%	100.0%	100.0%